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ABSTRACT

With a quarter of the country's children enrolled in Medicaid, the program has become an extremely important source of funding of all public health care for children and now provides half of all spending on public mental health systems. In 2002 the Bazelon Center undertook to examine whether Medicaid-eligible children were, in fact, receiving an expanded range of services in their communities. Working with local advocates, the Bazelon Center convened focus groups of parents with children in two states with relatively comprehensive Medicaid plans, New York and Oregon. This report summarizes findings from the 68 parents of 86 children and adolescents who took part in the six focus groups. While most Medicaid-eligible children with serious mental or emotional disorders continue to be served through traditional fee-for-services arrangements, some states have shifted all or part of their child mental health services to managed care programs. Researchers wanted to learn about differences, if any, between a fee-for-service state and a managed care state. Oregon has a managed care Medicaid system while in New York, Medicaid services for children with serious mental disorders are funded through fee-for-service. However, the similarity of the parents' accounts in the two states suggests that the differing structure of the programs has little effect on the ground. On paper, New York and Oregon describe a wide range of intensive community services for children through the psychiatric rehabilitation services category of Medicaid, but many parents in both states reported that their children seldom had access to more than basic medical and therapy services. An appendix contains the focus group methodology. (GCP)

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No One's Priority

The Plight of Children with Serious Mental Disorders in Medicaid Systems

A REPORT ON SIX FOCUS GROUPS IN TWO STATES

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This report is available online at www.bazelon.org, as are two more detailed reports of findings from each state. Paper copies of *No One's Priority* may be purchased for $12 each. No One's Priority and the two state reports may be purchased as a package for $30 (shipping and handling included) from the Bazelon Center's online bookstore at http://store.bazelon.org or by sending a check or money order to:

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No One's Priority

The Plight of Children with Serious Mental Disorders in Medicaid Systems

My dearest wish is for my son to be able to be maintained at home. He's been at residential facilities and hospitals on and off since he was seven years old. I have asked for support from the county and have been denied any kind of financial support. I've been denied and told that there were no services available, period, to maintain him in the home. The county had the money to maintain him in a residential facility or a hospital, but not maintain him at home. (New York parent)

Serious mental disorders affect millions of children. According to the United States Surgeon General, as many as 11 percent of all children in the United States have a mental disorder that significantly impairs their day-to-day functioning.[1] Most of these children can live at home if they and their family receive at least a minimal level of appropriate services. Indeed, a wide range of effective treatments exists for children with mental health care needs,[2] and the effectiveness of services for children with the most serious disorders has improved significantly over the last decade.

As the President's Commission on Mental Health has stated, "mental illness is very common and very disabling" but "with effective treatment, services and the support of families, friends and communities, the possibility of recovery is no longer elusive."[3] The words of the parents quoted in this report make it clear that many families are willing to go to extraordinary lengths to care for their child at home. But to provide the support that the President's Commission finds necessary, they need the help of the public mental health system—generally funded through the Medicaid program.

With a quarter of the country's children enrolled in Medicaid,[4] the program has become an extremely important source of funding of all public health care for children and now provides half of all spending on public mental health systems. In 1999, the Bazelon Center for Mental Health Law reviewed states' Medicaid service definitions and produced a report on the recent expansion of child mental health services in state Medicaid plans.[5]

That report documents how, over the past decade, states have adjusted their Medicaid programs to include a wider array of effective home- and community-based mental health services for children. States use several Medicaid categories to cover both basic mental health treatment (e.g., therapy, medications and crisis services) and intensive community services, such as case management, in-home services, day treatment, mentors and therapeutic foster care.

Under Medicaid's Early and Periodic Screening, Diagnosis and Treatment (EPSDT) mandate, children enrolled in the program are entitled to any medically necessary Medicaid mental health service. But describing a service in the state's Medicaid plan is only the first step to providing access. Whether children can obtain those services when they need them depends also, and crucially, on whether the service is more than a commitment on paper—whether it is actually available in the community.

In 2002, with support by the William T. Grant Foundation, the Bazelon Center undertook to examine whether Medicaid-eligible children were, in fact, receiving an expanded range of services in their communities. As one aspect of our investigation, we wanted to learn first-hand how parents of children with the most serious mental disorders perceived their child's access to needed services. Working with local advocates, the Bazelon Center convened focus groups of parents with children in two states with relatively comprehensive Medicaid plans, New York and Oregon.[6] This report summarizes findings from the 68 parents of 86 children and adolescents who took part in the six focus groups. (For more information on the focus groups, see appendix.)

We chose Oregon and New York because, compared with other states, they have described a relatively strong mental health benefit for children in their Medicaid rules. Yet they differ in organization of their Medicaid programs. While most Medicaid-eligible children with serious mental or emotional disorders continue to be served through traditional fee-for-services arrangements, some states have shifted all or part of their child mental health services to managed care programs. We wanted to learn about differences, if any, between a fee-for-service state and a managed care state. Oregon has a managed care Medicaid system while in New York, Medicaid services for children with serious mental disorders are funded through fee-for-service. However, the similarity of the parents' accounts in the two states suggests that the differing structure of the programs has little effect on the ground.

The array of services listed in each state's Medicaid plan is shown in the box opposite. On paper, New York and Oregon describe a wide range of intensive community services for children through the psychiatric rehabili-

SERVICES DESCRIBED IN EACH STATE'S MEDICAID PLAN

New York Medicaid Services

Outpatient Clinic Services
Assessments
Individual and group psychotherapy
Family education
Crisis services
Partial hospitalization
Physician services, including medication management
Prescription drugs

Community Rehabilitation Services
School-based day treatment
Other day treatment
Therapeutic preschool
Therapeutic foster care
Independent living skills training
Family teaching homes

Targeted Case Management
for children with serious mental disorders

Inpatient and Residential Services
Psychiatric hospital inpatient services
Residential treatment center services
Group home services

Home- & Community-Based Waiver Services
In-Home services
Individual care coordination
Respite care
Family support
Crisis response
Skill building

Oregon Medicaid Services

Outpatient Clinic Services
Assessments
Individual, family and group psychotherapy
Crisis services
Partial hospitalization
Physician services, including medication management
Prescription drugs

Community Rehabilitation Services
Intensive home-based services
School-based day treatment
Other day treatment
After-school programs
Family wraparound services
Therapeutic nurseries
Therapeutic foster care
Therapeutic proctor care
Individual psychosocial skills development

Targeted Case Management
for children with serious mental disorders

Inpatient and residential services
Psychiatric hospital inpatient services
Residential treatment center services
Group home services

tation services category of Medicaid, but many parents in both states reported that their children seldom had access to more than basic medical and therapy services. Intensive community supports through day treatment, in-home services, case management, therapeutic foster care and other services are written into each state's Medicaid benefit, but the parents in the focus groups found these largely unavailable or, when offered, provided in insufficient amount to be effective. Few of the parents said their children received a package of services that included both medical care *and* necessary rehabilitation services.

In both states, the families of the children who were able to secure such a service package—often only after persistent advocacy—expressed satisfaction with Medicaid and reported that their children were progressing relatively well, demonstrating that children do better when systems provide effective evidence-based services in sufficient range and amount.

The Parents' View

Notwithstanding logistical differences between the states' service programs, the families in all six focus groups made remarkably similar comments. A pattern of serious problems emerged from their statements that their children lacked access to needed services.

- Systems were crisis-oriented and furnished only minimal services once children were identified as needing help. This led to frequent—and, parents felt, unnecessary—deterioration and crises.

With my 11-year old, I knew something was wrong with him at about six or seven months old, and nothing got done until he was eight or nine. And I went through a lot of different systems and evaluations. (Oregon)

- Although parents had recognized their child's mental illness at a very young age, they said that public agencies (mental health, schools, child care) routinely ignored their requests for help. This even occurred when there was information suggesting that a very young child needed mental health services, such as a record of birth to a drug- or alcohol-abusing mother.
- Even when children's mental health needs were recognized, many families recounted long delays before they could obtain services.

But if I had somebody...come into my home and teach me...certain things that I should know about my child...it would have helped. (New York)

- Families reported receiving little education about their child's disorder and no training to assist them in managing their child at home (such as de-escalation techniques).
- Many parents said that their children had almost no access to intensive community rehabilitation services, such as home-based services, day treatment, school-based services, behavioral aides or mentors. Children in some localities had to be sent out of the area—some even out of the state—to obtain more intensive services.

My nephew is in [another state] for services because no services for him were available—neither in the county or in the state. (New York)

Even when services were available, the parents noted, they were often ineffective because they were furnished infrequently or inappropriately or were provided by staff the parents believed to be unqualified.

- Parents found it particularly difficult for their children to get appointments with a psychiatrist. Too few child psychiatrists are available, they said, and even fewer accept Medicaid.

Getting in to see a psychiatrist is impossible. You get in and there's a three-month wait for an appointment. To get her meds re-evaluated another three months, and then in the meantime, she was off the deep end and out of her mind. (Oregon)

- Case managers, parents stated, if available at all, were inexperienced, poorly trained and burdened with such high caseloads that they could not help the families.
- Therapy was provided infrequently, many parents reported, citing intervals of up to two months between sessions. While this

approach increases the number of children who receive some mental health services through the public system, such infrequent sessions do little to help children with serious disorders.[7]

But the child psychiatrist is an iffy proposition. That goes back and forth. Sometimes there's one and sometimes there isn't. (New York)

Individualized service plans are a hallmark of good care for children with serious mental disorders, but many parents in both states reported that services were rarely tailored to meet their child's needs.

You mostly have to take what they have to offer. I mean sometimes they say, "Well, if he doesn't like so and so, we'll find someone else." Well, he better like her because I tell you the waiting list is way too long. (New York)

- Despite diverse service elements, both states' Medicaid programs placed a heavy emphasis on medications and limited therapy sessions, even though many families said that what they needed was access to more intensive services—in-home services, day treatment or other supports for their child, in combination with medication and therapy.
- Parents of adolescents reported that age-appropriate services for their teenagers, such as life-skills training to enable them to transition to adult roles, were rarely available.

So, I'm concerned about their ability to function as they get older. How are they going to be on their own and take care of themselves? (Oregon)

- Many parents said they encountered crisis systems built around general medical emergency rooms or other patched-together responses. Mental health mobile crisis units were rare.

Families also reported serious problems in obtaining 24-hour care when, for lack of necessary community services, their children deteriorated to the point of requiring residential services. They said their children would end up on long waiting lists for scarce residential services. Once a child was in residential care, parents in New York reported, discharge planning was particularly poor and the children generally returned home with no plan in place for receiving services in the community.

I had to leave my job, take a leave at home and be held hostage in my own home for a whole year before he was even considered. Then they told me he was on a list. I didn't even believe them because how could I? I had lost all hope. (New York)

Parents in both states found schools failing to respond appropriately to their children's needs, despite the mandate of the Individuals with Disabilities Education Act's (IDEA) that children with "emotional disturbance" be provided special education and related services. According to parents, many schools lacked school-based mental health services and some had no specialized day programs for children with mental illnesses. Some parents complained that schools, by failing to identify children's mental disorders, denied their children an opportunity to access what services were available.

It's damage control in those classrooms. (Oregon)

Particularly in Oregon, parents who could not obtain services for their child said they were often advised to seek services through the child welfare system. Oregon has a law that allows for parents to enter this system voluntarily, but even so some of these parents said

She was institutionalized this summer, and they required me to sign over custody to the state. That's something if your kid was awaiting a heart transplant they wouldn't require you to do, but since it was a mental illness, they made me relinquish her custody. (Oregon)

they were told they would have to give up custody of their child if they wanted to access public mental health services.

My son didn't really get any help until I had him arrested.... I had to call the police on him and say that he hit me, which he did. But I kind of thought to myself when I woke up that day, "Okay. Today I'm going to let him hit me. We're going to play a game." (Oregon)

In both states, some parents reported being told they could only obtain needed services through the juvenile justice system and being advised to call the police.

The parents' observations reflect the disintegration the Bazelon Center has seen in all states' mental health systems.[8] Their reports paint a picture inconsistent with the comprehensive list of services in the states' Medicaid plans. In both states, the multiple problems they cited illustrate key failings in public mental health for children.

- Public systems respond too late with too few services to meet children's needs and the services provided are sometimes inappropriate.
- What services are provided fail to prevent deterioration in the child's condition, resulting in behavior so extreme that children eventually come to the attention of the juvenile justice authorities or creating a situation so desperate that the family is driven to call the police.
- Cost-shifting between mental health, education, juvenile justice and child welfare agencies creates an unresponsive system where children fall through the cracks or are served in inappropriate venues.

They all want to pass the buck.... The school didn't want to make a referral because they would have had to fund it. Mental Health doesn't want to make the referral because they would have...had to fund it. DSS didn't want to make a referral, they would have had to fund it. So I have to go and yo-yo back and forth (New York)

Several families reported that mental health providers' initial response to their child's behavioral problems was to attribute the child's behavior to poor parenting skills or to suspect some type of abuse. Even families with adopted children, who were likely to have behavioral problems related to their premature birth or maternal substance abuse, said they had been blamed. This is a familiar theme regarding mental health systems, contributing to the disenfranchisement that parents of children with mental health needs have long felt and their reluctance to seek help or to advocate aggressively when their child's needs go unmet.

My son suffers from phobias since he was a kid. He's going to be 15 and he still sleeps with the light. The doctors...ask me, "has he been sexually abused?" Like pointing at me.... That bothers me. (New York)

I am concerned about services. I don't want to lose my son. I want to get my son help now before he goes and robs a store or something and then he gets taken away. (New York)

Without exception, the families expressed a strong desire to keep their children at home and to avoid any out-of-home placement, especially child welfare and juvenile justice placements. Many went to extraordinary lengths to adapt to their situation and take care of their child.

However, typically, as children grew older (and bigger), families said it was ever more difficult to cope with behaviors that were symptoms of the child's illness. Many reported being on waiting lists for residential care—their child considered ill enough to need 24-

hour professional care, but left with a family who received no special training, no respite and little if any support from public systems.

The impact on parents, siblings and others was often extreme, the parents said, yet they continued to do all they could to cope.

> *It gets to you after three or four days of the banging-of-the-head stuff, and the big fits and stuff, you get to where you're stressed out and can't cope either. And you start yelling and that shoots your kid right off the deep end. (Oregon)*

> *He came home on a stipulation that he was going into residential placement. So he came home to us for a six month period knowing that he had to go into residential placement, but there wasn't any wraparound service. There was nothing offered to us. We just had to take this child home that was supposedly so out of control and unstable that he had to be in residential placement. And keep him safely at home until that period in time when a placement became available. With no services offered to us except for counseling at the clinic. That was all we were offered. (New York)*

Implications for Public Policy

These two states have defined a relatively strong mental health benefit for children in their Medicaid plans. New York and Oregon are also among the states that allocate significant resources to public mental health services, ranking 2nd and 18th respectively in per-capita spending on mental health nationally.[9] Despite differences in the organization of the states' Medicaid programs (fee-for-service in New York, managed care in Oregon), the issues recounted by families in both states were remarkably similar. If what the parents in the focus group had to say is indicative of the plight of most children with serious mental disorders in these two state Medicaid programs, there is good reason to believe that families in other states experience similar problems in accessing needed services.

> *They set really high criteria. If your child doesn't meet everything, then they just don't offer that service to you. But your child could have one or two of the warning signs, and they haven't escalated to that. They don't want to nip it in the bud. They want to wait until they're really bad. (Oregon)*

Recommendation: Access to effective home- and community-based services

Issues relating to children with serious mental disorders are not now a priority for public mental health systems. Most public systems are adult-focused and most of their resources are allocated to services for adults. The dismal picture of denial of access, extraordinarily inadequate levels of service and lack of appropriate evidence-based services painted by the parents in our focus groups strongly suggests the urgent need for far more attention to reforming children's mental health systems.

> *And there just hasn't been a lot of support or recognition. It's like, if they're not starting fires or doing this, then okay. They're okay. (Oregon)*

States should ensure that the appropriate array of intensive community mental health services is actually available to children with mental health needs. Children must receive a level and a range of services sufficient to improve their conditions. The most critical

> *The staff at the [health plan don't know what they cover. Everybody has a different answer sometimes. At the place that you go to, they may think a different thing than the people that you call at the insurance company. (Oregon)*

I'm trying to tell them now that children don't normally bite themselves and pull their own hair out. And my daughter's doing this and no one will listen. She's four. And nobody will listen. (Oregon)

of these services are intensive in-home services, therapeutic foster care, mentors, multi-systemic therapy, day treatment, case management and family education to manage the child's disability. Each of these services is cited as effective in the Surgeon General's report on mental illness.

Recommendation: Mobile crisis teams

There were also times when we lived in an emergency room for a few days, waiting for a bed to open (Oregon)

Parents in both states reported distress at the response they received when their child was in crisis. Instead of mental health crisis services, families said they had had to turn to general hospital emergency rooms ill-equipped to handle children in psychiatric crisis, which often simply sent them home with the suggestion to "call mental health in the morning." If they were particularly afraid for their child's safety, some parents said, they were advised to call the police. The very few families who had access to mobile mental health crisis teams said that these crisis services were beneficial.

Then you're like there to 1 or 2 o'clock in the morning and they say you can go home. And my child was hitting me and kicking me with a male nurse in between us. Get yourself and go home now. (New York)

Mental health crisis teams should be available in all communities. At a minimum, community mental health programs should have emergency services available 24 hours a day, seven days a week. Other medical specialities provide such emergency care as a routine practice; mental health response is no less urgent.

Recommendation: Early intervention

And I saw it in him when he was about 13 months old for the first time. I thought that this is odd behavior. And by the time he was two, he had been booted out of five different day cares...The gap in identifying services for him and identifying a diagnosis and offering him adequate treatment was almost 10 years. (Oregon)

Early intervention that could have prevented deterioration and avoided significant future problems and future costs is rarely available, the parents noted. In both states, families reported knowing from infancy or early toddlerhood that their child had a major problem. Typically, they said, formal helping systems only acknowledged these needs and provided formal assessments and diagnosis many years later. Some parents reported delays of between six and 15 years. The experience of a small group of families in Oregon whose children had been identified by their local Head Start program through a special initiative demonstrates a more workable approach. Families in the group were able to obtain needed services and reported that their children were doing relatively well.

[At age 5] she tried to put a pillow over a child's head to kill her. Now that she was a risk to herself and others have I finally got a mental health caseworker. (New York)

Mental health services for very young children need to be expanded so they and their families receive effective interventions when children are identified. One proven approach is for child care and preschool programs to have access to necessary mental health expertise to enable young children with significant mental health care needs to be identified and referred to early intervention services.

Recommendation: Education of and participation by parents

Families reported that, throughout their child's life, they were accused and blamed for the behaviors that resulted from their child's mental illness. They said that professionals in mental health and other child-serving systems—including teachers, school administrators, child welfare workers and juvenile justice officials—dismissed their parental insights, instead trying to "fix" the parents. This response further delayed access to appropriate services for children. Failure to change these attitudes hurts parents and wastes precious time and resources as children's needs are misread.

It wasn't until [he was] ten-and-a-half when the Ritalin started working. And the school, prior to diagnosis of that ADHD, kept saying, "What are you doing? What are you doing?" Now they're realizing there's something wrong with him and it's not me. (Oregon)

States should infuse principles of a child-focused, family-friendly system of care into all levels of their systems: direct care, local and state administrative levels, and policy levels. All systems should engage parents as partners in service delivery. To more effectively furnish services, all front line staff in all core agencies—mental health, education, child welfare and juvenile justice—need to be able to recognize mental disorders and be fully conversant with child-centered, family-focused care principles.

I found out by word of mouth from other parents who have ... older children than mine and have been through and eventually found what they might be able to get. (Oregon)

Recommendation: School-based identification and services

The parents almost uniformly identified schools as problematic. They said that mental health services in schools (billable to Medicaid in both states) were almost nonexistent in most places. Schools routinely blamed parents, they reported, and denied their children access to the special education required by the federal Individuals with Disabilities Education Act (IDEA). Day treatment programs were rare and the parents found those that existed overburdened. Unable to appropriately address children's mental health needs, schools instead suspended children—some as early as preschool. Other children dropped out or were expelled from high school.

I had to...almost close down the school fighting.... [After ten months] I said, "Look, I don't care who pays for a psychological evaluation." Because the school was saying, "Well, DSS has to." DSS was saying, "It's the school's problem." and I just got mad... By the time it got to the board of education, they looked at me and they said, "How did you manage?" (New York)

More school-based day treatment services need to be developed. In addition, schools should revise their policies to more accurately identify children with "emotional disturbance." These children are being overlooked and denied the services they are entitled to under IDEA. As a result they are deteriorating and will require more intensive and expensive care later in their lives.

Recommendation: Interagency collaboration

Because their mental health needs are neglected, children in at least half the states often are placed in the child welfare or juvenile justice systems.[10] In some cases, families relinquish custody or enter into voluntary agreements to place their child in the child welfare

They all want to pass the buck.... The school didn't want to make a referral because they would have had to fund it. Mental health doesn't want to make the referral because they would have been [the one] that had to fund [it]. DSS didn't want to make a referral, they would have had to fund it. So I have to go and yo-yo back and forth. I finally got them all in a meeting together and said, "Somebody better make the referral." (New York)

system just to access services. As children age, their behaviors often bring them in contact with law enforcement and juvenile justice. These outcomes are unnecessary, generally ineffective and often damaging to families. Nonetheless, children's mental health needs are not ever likely to be met solely through public mental health systems. Agencies need to work together, with similar goals and in a coordinated way, to improve outcomes for these children.

Federal, state and local agencies need to improve collaboration to ensure that all systems have the same goals and objectives with respect to children's mental health care needs. Duplication, gaps and waste across the mental health, education, child welfare, juvenile justice and substance abuse systems must be eliminated.

Recommendation: Coordination and case management

When my son got into...case management, I felt like one of the lucky ones who didn't have that long of a wait. Maybe it's because I got loud and very demanding. (New York)

Children with complex needs require a case manager to help organize and coordinate services. Surprisingly, given that case management is a fundamental part of most adult mental health systems, many of the focus group families said they did not have a case manager and quite a few did not know that such a service existed. Case management services ought to be available to all children identified as having serious mental disorders, particularly when they are, as these children were, involved with more than one child-serving system. It is also extremely important that caseloads be limited to a reasonable size, so case managers can more effectively serve children with complex needs and their families.

Nobody actually told us about them [case managers], we just fell into it. (Oregon)

States should ensure that every child with complex mental health needs who is using multiple services from multiple systems has a single case manager to coordinate care and monitor the need for further interventions.

Recommendation: Parents' involvement in policy decisions

I think I could have gotten a lot more services had I known about them. I could have advocated for them. (Oregon)

Finally, the parents in these focus groups showed considerable insight about how systems really work. Family involvement in policy boards is common in public mental health, but the key factor is whether families have a meaningful role or are merely token participants.

Policymakers in decision-making bodies at the state and local level should engage families of children with serious mental disorders in their deliberations. As demonstrated by these focus groups, families have acquired—often painfully--and are willing to share very valuable knowledge about how public policies translate into practice.

Conclusion

Comments by the parents in these focus groups serve to illustrate a number of serious problems with child mental health service systems in this country.

As the President's Commission on Mental Health has stated, "when the system fails to deliver the right types and combination of care, the results can be disastrous for our entire nation: school failure, substance abuse, homelessness, minor crime and incarceration." The Commission emphasized that the "mental health maze" is more complex and more inadequate for children than for adults and that "families do not know where to turn."[11] These concerns were echoed by the parents who participated in this focus group study.

I am seriously considering telling the judge to remove him. I don't feel now there is hope because there is no place to put him. Obviously nowhere they're going to find. He doesn't need juvenile jail, he needs therapeutic intervention. If there is nothing available what the heck do I do? (New York)

Children do not outgrow serious mental disorders that are left untreated and the long-term results of systemic failings affect us all: disruption in school, substance abuse, unemployment and dependency, homelessness and an increase in minor crime.

The results reported by the few families in this study who had received appropriate and early services confirm that we know what works. So why do we give such low priority to providing two to three million children the services that can improve their lives?

Once we zeroed in and found some nice people with some kind of heart. One social worker, she said, "I'm going to help you because you've been through so much and you've been thrown here and here. I don't want her to go through the system, get caught up in it. She needed to get the help she needed." She helped me. (New York)

For too long, services to children and their families have been given a low priority by public mental health systems. Likewise, mental health has been poorly addressed by other child-serving systems. Families may do their best, but the odds are against them when public systems turn their backs on the mental health needs of their children.

The parents we interviewed believe—and the Bazelon Center concurs—that major reform is needed in the state systems for providing services to children with mental disorders. Our nation's children deserve better.

> *It's like knocking your head against the wall. Nobody wants to seem to really listen. And it's like mind boggling that it takes a long as it does to get the right services for these kids. (New York)*

Notes

1. Five percent of all children have a serious mental disorder that results in extreme functional impairment, and 11 percent have disorders that cause serious functional impairment. U.S. Department of Health and Human Services. *Mental Health: A Report of the Surgeon General.* Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health, 1999.

2. *Id.*

3. The President's New Freedom Commission on Mental Health (October 29, 2002). Interim Report to the President. Available at: www.MentalHealthCommission.gov.

4. *The Federal Budget for Fiscal Year 2003,* Department of Health and Human Services, Washington, D.C., February, 2002.

5. Bazelon Center for Mental Health Law. *Making Sense of Medicaid for Children with Serious Emotional Disturbance.* Washington, D.C, 1999.

6. It should be noted that these focus groups preceded the recent drastic budget cuts in Oregon, which significantly reduced Medicaid coverage in that state.

7. Angold, A., Costello, E. J., Burns, B.J. et al. Effectiveness of Nonresidential Specialty Mental Health Services for Children and Adolescents in the "Real World." *Journal of American Academy of Child and Adolescent Psychiatry*, 39:2, 154-160 (2000).

8. Bazelon Center for Mental Health Law, *Disintegrating Systems: The State of States' Public Mental Health Systems.* Washington, D.C. 2001.

9. *Funding Sources and Expenditures of State Mental Health Agencies, Fiscal Year 1997.* National Association of State Mental Health Program Directors Research Institute, Inc., Alexandria, VA. July, 1999.

10. Bazelon Center for Mental Health Law, *Relinquishing Custody: The Tragic Result of Failure to Meet Children's Mental Health Needs,* Washington, D.C. 2000.

11. The President's New Freedom Commission on Mental Health (October 29, 2002). Interim Report to the President. Available at: www.MentalHealthCommission.gov.

12. Barry Brauth. New York State Office of Mental Health. (February 2002). Patient Characteristics Survey, 1997, Albany, NY.

13. Ralph Summer, Office of Mental Health and Addiction Services, Oregon Department of Human Services. (February 2002). Oregon Medicaid Enrollment, 2002, Salem, OR.

Appendix

Focus Group Methodology

Recruiting families on Medicaid who are willing to participate in a two-hour focus group is difficult. These families often face financial hardships and many lack transportation. Accordingly, a targeted recruitment strategy was selected as the best approach to locate families with children on Medicaid with a serious mental and emotional disorder. Focus group participants were recruited through Families Together in New York State and the Oregon Family Support Network (OFSN), state chapters of the Federation of Families for Children's Mental Health. Families receiving assistance from the federation's chapters have children with serious disorders, and we believed that recruiting families who have developed positive relationships with Federation chapters would increased the likelihood that they would commit their time to participate in the study. The invitation to participate did not ask whether the families were satisfied with the services their child(ren) had received.

In addition to Medicaid eligibility, the study required that the family include children with a serious mental and emotional disorder who had received mental health services via Medicaid in the past year. Because many of these families had received support and assistance in accessing the mental health services from the Federation chapters, they represented the best-case scenario: parents who are informed about their child's disorder, the services they needed, and on how to maneuver through the system.

We used various approaches to recruit parents, including announcements in newsletters and distribution of flyers to programs serving children with serious emotional disturbances, such as support groups, child mental resource centers and county departments of mental health. Families were screened to ensure that their children were Medicaid-eligible and that they had a diagnosis of serious mental disorder. No random selection was involved. All eligible families were invited to participate.

The focus group topic guide was developed by the Bazelon Center with input from Families Together, OFSN and the Bazelon Center's Institutional Review Board (IRB). The topic guide included questions on the following areas: 1) identification and diagnosis of child's mental disorder; 2) knowledge of mental health services covered under the state's Medicaid plan; 3) access to listed mental health services; 5) amount of services received; 4) satisfaction

with services received; and 6) suggestions for improving the system. A short survey asked about the participant's relationship to the child and the child's age, diagnoses and mental services received in the past year. The survey, topic guide, consent form and research protocol were reviewed and approved by the Bazelon Center's IRB in January 2002.

Parents completed the survey and then participated in the focus group for approximately two hours. As is standard focus group policy, participants were paid for their time. Child care was also made available. Each of the focus group discussions was transcribed.

Focus group participants in New York discussed their experience with 40 children and those in Oregon discussed experience with 46 children. Most participants in all groups were mothers. Children were primarily male and tended to be older (ages 7-18) with multiple mental health problems. Diagnoses most often reported were:

- attention-deficit/hyperactivity disorder or attention deficit disorder;
- depression;
- learning disorder;
- conduct disorder;
- oppositional disorder/oppositional defiant disorder;
- post traumatic stress syndrome.

We compared the minority representation of our focus groups with the two states' demographic data about children in their Medicaid programs. New York reports that African-American and Hispanic children account for 56 percent of children on Medicaid receiving services at state-licensed facilities.[12] Our focus group was closely aligned, reflecting 59 percent African-American or Latino members. In Oregon's Medicaid program, African-American or Latino children account for 28 percent of enrolled children; our focus group, having little Latino representation, included only 9 percent.[13]

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